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ABSTRACT

To meet the needs of adolescents on adult wards of the Massachusetts State Hospitals and inpatient community mental health centers, and to carry out the educational mandates of Chapter 766 and P.L. 94-142 (the Education for All Handicapped Children Act), the State Hospital Education Programs (SHEP) system was developed. SHEP adheres to three basic objectives: (1) to facilitate team evaluation and individual education plans: (2) to provide direct educational programing and services: and (3) to facilitate linkages with local educational agencies and smooth transitions to community based programs. Development of SHEP since its inception is considered, and major thrusts of SHEP are pointed out. (SBH)

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ED CONFERENCE PAPER

DEINSTITUTIONALIZATION: Dollars and Sense

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DEINSTITUTIONALIZATION: DOLLARS AND SENSE

In the past fifteen years, mental health systems across the country have attempted the arduous task of deinstitutionalization. The process of deinstitutionalization is not necessarily limited to reducing days of hospitalization by discharging those clients who are capable of functioning in an appropriate community setting. The process also involves preventing inappropriate hospitalization, as well as nurturing a sensitive and responsive community environment in which this population can lead full and productive lives. Federal court decisions and subsequent legislation has ruled that the mentally disabled have the right to live in the most appropriate, least restrictive environment. As a result, the Commonwealth of Massachusetts has taken the lead in reducing the population at state institutions. In the past four years, the hospital census has decreased 40%, to the point where only 2,800 individuals currently reside in state hospitals. Along with this meritorious attempt to remove individuals from the often times debilitating effects on institutional life, provisions had to be made to identify or provide services within the community which would meet the special needs of these individuals and therefore facilitate the mainstreaming effort.

In line with this philosophy, the Massachusetts Department of Mental Health has implemented a community based network which provides mental health services at the local level. This approach is based on the premise that services delivered within this least restrictive framework offer a natural environment to promote healthy growth and the development of the total person. As an ideal, the ties to family and neighborhood groups remain intact and provide the necessary support system for the individual.

The organizational structure of the Department of Mental Health is divided into seven geographical regions within the Commonwealth of Massachusetts. Each region is directed by the Regional Service Administrator. In addition, there are forty-one catchment areas, with each region having anywhere from four to eight areas. These areas are administered by an Area Director.

The system is primarily decentralized with budgets and programs developed and implemented at the area and/or regional level. Central office develops policy, regulations and standards for client care.

In 1976, the Department of Mental Health conducted a massive needs assessment which analyzed every client who was residing in state hospitals. It was discovered that 80% of these clients could live in the community if well funded programs existed. Unfortunately, the availability of residential and support services in the community were minimal which often times delayed the clients from being discharged.

Due to this identified need as well as humanitarian concern, the development of a comprehensive community mental health network heightened.

The state agency arrived at concrete solutions to deal with this complex endeavor. First, the Department rearranged its administrative structure. Prior to this, state hospitals were isolated administratively and programmatically from the mental health system and the community in general. The Area Director now became responsible for a specific unit at the hospital which houses clients from that particular area. The Area Director was delegated the responsibility of clinical staff assigned to that unit for discharged clients. Second, affiliation agreements with general hospitals were initiated so that they would develop psychiatric units to provide inpatient services for the acute psychiatric population. Third, with the development of more community mental health centers and mental health clinics, more aftercare services were available to discharged clients. These services included outpatient counseling, emergency services, crisis intervention and day activity programs. Lastly, more resources were being spent to develop community based mental health programs. At one time, 80% of all mental health resources were allocated to the institution. Since then resources have been shifted gradually to community sites so more clients are discharged into community programs.

Currently, approximately 60% of all mental health resources are allocated to community programs. As the hospital census is reduced further, more resources will follow the discharged client into the community.

During the course of this development the emphasis has been on the most disabled, disenfranchised adult population. As a result, services to children and adolescents were at least initially, not a priority.

As a result of a comprehensive data collection in 1977 and 1978, it was found that at any given time there were approximately 150 adolescents on adult wards of the Massachusetts State Hospitals and the inpatient community mental health centers. Adolescents on these wards were short term and acute admissions with clinical diagnoses ranging from schizophrenia to depression, from character disorders to drug addiction. Educationally these patients (ages 14-21) were receiving no services.

Because of the identified need apparent from this data and to carry out its educational mandates of Chapter 766 and PL 94-142, the State Hospital Education Programs (SHEP) were developed jointly by the Department of Education via the State wide Project for Priority Populations and the Department of Mental Health via Project COHORT. DOE's role was to fund the program - the personnel and materials; DMH was to coordinate the interfacing between the DOE staff and the Department of Mental Health hospital, area, and regional staff.

By May, 1978, there were eight SHEP programs at all state hospitals and all five community mental health centers. To be eligible for the educational services an

adolescent had to be admitted to an inpatient unit at a Department of Mental Health facility, be under 22 years old and be without a high school diploma.

Although each program is unique and has developed according to staff expertise, student needs, and the environment in which the services are located, all programs adhere to three basic objectives:

1. to facilitate TEAM evaluations and Individual Education Plans
2. To provide direct educational programming and services
3. To facilitate linkages with local educational agencies and smooth transitions to community based programs

Ultimately the goal of both the Department of Mental Health is to insure that all students receive educational and vocational programs which develop their abilities to function as individuals in an environment typical to their age group and assist them in moving to living/working environments that encourage the growth of these abilities.

In 1978 these SHEPs experienced growth pains all across the state. Clinical staff at the institutions were initially very resistent to this new educational component. At this early stage DMH's Project COHORT facilitated meetings with appropriate ward staff and the teachers. Area and regional DMH personnel also attended these meetings when appropriate. Advisory boards were formed to lend support to the program and monitor fiscal and programmatic matters.

Initially the curriculum was delivered on a one-to-one basis, often times on the wards where the adolescents lived. As the programs became more stable, rooms were identified for large and small group instruction. Formal space agreements were agreed upon.

Services were classically academic when the SHEP's began. Basic subject areas - math, reading, English, science, were presented in a traditional manner. However, as the teachers became more confident and more sensitive to the needs of this unique population, traditional models of curriculum and delivery became less important. More emphasis was placed on real life experiences - career awareness, self-help skills, sexuality discussions. Field trips became an integral piece of the program. Adolescents went bowling, to movies, to libraries, job sites, bus trips, bicycle rides, rock climbing, camping. Programming still occurred at least two hours daily for any adolescent in a SHEP. Some programs were offering 3-4 hours a day.

Local school systems gradually became involved with the SHEP's as a result of a strong outreach component from the SHEP. Schools participated in the development of the Individual Educational Plans.

High School credit was given to accredited SHEP courses. Regional Vocational Schools also recognized courses at the SHEPs and offered their courses for high functioning SHEP adolescents.

Not only did these programs deliver services to this low incidence population, but they took some responsibility in placing adolescents after their discharge from the state hospital. If an adequate placement could be found, there was a good chance these adolescents would not be readmitted to an inpatient ward of a state hospital. Project COHORT aided the SHEPs in identifying various placements in each region. Project COHORT coordinated services with the Massachusetts Rehabilitation Commission and the SHEP to provide supportive services to the residential placement. MRC primarily provides vocational placements.

As more adolescent vocational needs were identified, programs sought resources to fill the gaps in their existing services. With Project COHORT's networking, CETA was tapped for in-school training and jobs. Local CETA youth coordinators became more sensitive to this special population through informal meetings with the SHEP staff. Tailored programs were developed to teach these adolescents about the world of work.

Formally, at the beginning of 1980, Project COHORT negotiated a training program with the Department of Manpower Development to train SHEP and other DMH staff around issues of CETA - proposal writing, funding cycles, supportive services. As a result of this project 20 new jobs were funded and CETA expertise was acquired by those participating SHEP staff.

Although these programs are over two years old, there are always problems. As the programs become more developed, as needs change, as expectations rise, new conflicts emerge. From the DMH standpoint, Project COHORT must take the responsibility of problem-solving with the programs, the areas, and the regions.

It does seem, at least on paper, the the SHEPs are taking <u>their</u> responsibility with the help of a community based network to support them. In fiscal year 1979 (July 1, 1978 - June 30, 1979) SHEP served 737 adolescents. In fiscal year 1980 (July 1, 1989 - June 30, 1980) SHEP delivered to 550. This is a reduction of approximately 185; 185 fewer admissions to the inpatient state facilities in Massachusetts.

As the programs grew in sophistication, changes had to be made. Several SHEPs began drastic metamorphases in 1979. They began moving off state hospital grounds and became their own "least restrictive environment". Four sites have and are accomplishing this arduous task.

Although comprehensive services (clinical and educational) had been flourishing at a SHEP in the northeast region of Massachusetts, movement was necessary for growth.

Two buildings were identified in a rural area 15 miles from the State Hospital. Twelve adolescents moved into this community in the summer of 1979 where they lived, worked, and learned in a more normalized environment. Presently there is an array of services: education, recreation, art, music, family counseling, individual life skills, and vocational training. The atmosphere is home-like and growth-motivating. Community experiences are a high priority in the program as is the attainment of a high school diploma.

There are still admissions to the State Hospital in that region. These adolescents receive tutoring this year but will receive a more comprehensive program next year including vocational, recreational, and community exposure.

Less developed, but still moving toward the goal of a least restrictive environment is a SHEP in the western part of the state which began in the fall of 1979. When clinically appropriate, SHEP students are bused to an educational program for a least two hours of services four miles from the state hospital where they are residing. This educational program is located in a school where other special needs adolescents are learning.

Very recently in the southeast region of similar set-up is just now underway. Two slots are available for SHEP adolescents to be bused to a collaborative program three miles from the state hospital on a daily basis. These two students will be integrated with six other community students for academic and vocational training.

The remaining SHEP students who are residing at that state hospital will continue to receive comprehensive educational services in a resource room on the grounds.

Finally, the SHEP in central Mass. has identified an unused building on the state hospitals grounds that may eventually be used as a residence. Presently, renovations done by the students will prepare this site for day activities.

These SHEPs strive to deal with those who have demonstrated years of serious emotional involvement. The intent is to get them out into the community after they have been admitted to the state hospital. That is one piece in the deinstitutionalization process. DMH also funds programs which attempt to prevent children from ever having to experience a state hospital admission.

Across the state the DMH provides early intervention services in 41 catchment areas. Seven of these 41 programs are jointly funded with the Department of Public Health. All programs provide therapeutic and supportive services for infants and young children from birth to three who have been identified as being at risk for mental, motor or sensory handicaps due to the presence of biological or environment risk factors. Multi-disciplinary teams emphasize and support the family as the primary care giver in utilizing resources to provide opportunity for optimum development.

Referrals and casefindings vary from program to program but all use at least two of the following: medical hospitals via pediatric nurses and/or prediatricians, community mental health centers, Visiting Nurses Association, other human service agencies and word of mouth. From recent data it is obvious that the case-finding network has improved and been refined. In fiscal year 1979, 1200 children were served; in fiscal year 1980, 1500 were served.

Staffing patterns vary too according to the needs of children and families, and fiscal constraints. All emphasize parent involvement.

An early childhood development specialist, a physical, or occupational and/or speech therapist, a pediatric nurse, a consulting psychiatrist and a pediatrician may all be part of the interdisciplinary team.

All Early Intervention Programs have a home component at which time parents are involved in their child's developmental services. Many too have a center based site located in various types of buildings - churches, fire stations, community mental health centers, and medical hospitals. Programming at the center-based site emphasize socialization activities, parent support groups, and developmental services.

Historically there have been some hookups with local education agencies, especially as the children turn two. All children have Individual Education Plans to make a smooth transition into schools or special programs.

These two major thrusts, that of servicing adolescents while they are hospitalized and attempting to mainstream them into their communities, and of preventing these adolescents as toddlers from ever approaching the inpatient wards, are crucial components in the complex effort to maintain as many people as feasible in their own communities.